



NINR FOCUS: END-OF-LIFE ISSUES

one in a series of focus papers on research directions
and NINR-funded research advances

As medical advances extend life expectancy, care at the end of life has become a national concern. People are living longer with chronic, complex, and multiple conditions that affect quality of life. Issues of end-of-life care include respect for the dignity of dying patients; treatment of symptoms like pain, fatigue, and depression; patient and family decision-making; advance directives; alternative therapies; and hospice and palliative care. The end of life is an important phase of life. Research is needed to help people of all ages and all ethnic and cultural backgrounds to live out their lives with the highest quality of care.

A Brief History of NINR's End-of-life Research Activities

The 1997 report from the Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, found widespread dissatisfaction with end-of-life care and many gaps in our scientific knowledge of this phase of life. In response, NINR sponsored a workshop on the symptoms of terminal illness, and NINR was later designated the lead Institute within NIH for end-of-life research. NINR studies on the management of pain and other symptoms, family decision-making, caregiving, advance planning, and the care of the elderly and the critically ill provided an important base of knowledge on which to build.

In 2000, NINR sponsored a performance of the Pulitzer Prize-winning play, *W/T*, about a professor of poetry dealing with a terminal diagnosis of ovarian cancer. This event, at the Kennedy Center in Washington, D. C., included a reception and a question-and-answer session with members of the cast and a panel of health care experts. Later that year, NINR held a community forum entitled *The End of Our Lives: Guiding the Research Agenda*. Speakers, panels, and audience discussions addressed palliative and hospice care, respecting patient dignity, treatment of pain and fatigue, conducting research in sensitive end-of-life settings, and cultural and ethnic differences toward the goal of achieving a "good death." Results from these forums helped to guide the future direction of NINR end-of-life research programs.

In 2001, NINR collaborated on a 6-part continuing education video series for nurses on end-of-life care. In these videos nursing educators discuss end-of-life experiences, family decision-making and advance directives, caregiving issues, and how to apply end-of-life research in practice.

Several working groups of researchers and clinicians, brought together by NINR in recent years, have explored new directions for end-of-life research. Topics have included end-of-life issues in AIDS, genetics diseases, and children with cancer, working with elderly populations, dealing with uncertainty, ethical challenges in palliative care research, and developing capacity for end-of-life and palliative care research. More information can be found on our website at: <http://ninr.nih.gov/ninr/>

As a result of this work, in December 2004 NINR co-sponsored the National Institutes of Health State of the Science conference, *Improving End-of-Life Care*. This conference brought together almost 1,000 health care practitioners from around the world, including nurses, physicians, social workers, and others who work with the dying, to evaluate the current state of the science in end-of-life care and to determine future directions for research. Some recommendations arising from the conference include: developing the research infrastructure for end-of-life care; enhancing communication among patients, families, and health care providers; including under-represented populations in research; and creating research networks to support coordinated, multi-site studies. The consensus statement from this conference is available at: <http://consensus.nih.gov/ta/024/EoLfinal011805pdf.pdf>

Recent NINR Findings on End-of-Life Care

Spirituality reduces despair. Interviews with terminal cancer patients found that spiritual well-being helped reduce feelings of depression and hopelessness and the desire to hasten death, and had a positive relationship with social support. Palliative care nurses should assess the spiritual beliefs and needs of their patients to help them achieve a sense of peace and meaning in their life. *Breitbart, Memorial Sloan-Kettering Cancer Center, 2003.*

Decline in the last year of life. Patterns of decline for elders in their last year of life typically follow one of four paths: Sudden death, Cancer, Organ failure, and Frailty. Decedents experiencing sudden death often maintain independent function until the end. However, those with cancer show a steep decline from normal function, those experiencing frailty have a gradual but continual decline, and those suffering organ failure tend to fluctuate between decline and improvement. Studying these patterns can improve current models of end-of-life care. *Lunney, National Institute on Aging, 2003.*

Caregiver strain. Family caregivers reported that many elderly decedents had lack of energy and appetite, drowsiness, dry mouth, pain, and dyspnea, despite hospice care. Many caregivers felt emotionally or physically drained, and two thirds had sleep disturbances. Although almost all decedents had health insurance, caregivers reported a high level of financial burden and many out-of-pocket expenses. *Tilden, Oregon Health & Science University, 2004.*

Documenting end-of-life wishes. Among a group of terminal cancer patients, less than half had an advance directive, although Whites were more likely to have one than Blacks. Those with an advance directive wanted to exercise control and avoid confusion. However, there was almost a 50% disagreement between patients and their caregivers on the desired treatment interventions. *Phipps, Albert Einstein Healthcare Network, 2003.*

Missed opportunities in end-of-life meetings. When a patient is dying in an intensive care unit (ICU), clinicians may meet with the family to explore the decision to withhold or withdraw life-sustaining treatment. However, an analysis of communication during these meetings found that clinicians often “missed opportunities” to address the concerns of family members, including: (1) failure to listen, (2) failure to acknowledge emotions, and (3) failure to explain ethical considerations or palliative care. *Curtis, University of Washington, 2004.*

Withdrawing life support. Most family caregivers involved in a recent decision to withdraw or withhold life support from an elderly relative reported strain in the process that led to uncertainty, guilt, regret, and anger. However, some caregivers accepted their role and believed they were doing the right thing. Afterward, these caregivers were more at ease with their decision and felt that they had learned from the process and grown closer to other family members. *Hansen, Oregon Health and Science University, 2004*

NINR Research Theme on End-of-Life Care

NINR has identified *Enhancing the end-of-life experience for patients and their families* as a Research Theme for the Future. Many Americans are dissatisfied with the way the healthcare system provides care for the dying, and NINR has an obligation to support research on end-of-life and palliative care across the spectrum of care settings, ages, cultures, and socioeconomic groups. The full NINR Research Themes for the Future document is available at: <http://ninr.nih.gov/ninr/research/themes.doc>

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The National Institute of Nursing Research (NINR) supports clinical and basic research to establish a scientific basis for the care of individuals across the life span. NINR-supported research seeks to improve the management of patients during illness and recovery, reduce the risks for disease and disability, promote healthy lifestyles, and improve the clinical settings in which care is provided, including problems encountered by families and caregivers. To accomplish its mission, NINR provides grants to universities and other research organizations and conducts intramural research and research training on the campus of the National Institutes of Health. These efforts foster multidisciplinary collaborations to ensure a comprehensive approach to research on illness and disabling conditions. NINR emphasizes the special needs of at-risk and underserved populations, and with the ongoing goal of implementing knowledge to reduce health disparities.

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